GAC Medicaid Transition Residential Services Work Group
1056 Woodbrook Conference Room, Dover
April 16, 2015 1:30 p.m. – 3:30 p.m.

Present: Libby Cusack, Families Speaking Up; Bill Monaghan, DE People First, Gary Mears, DD Council, Laura Waterland, Disabilities Law Program; Kathie Cherry, GACEC; Kyle Hodges, SCPD; Terry Olson, The ARC of DE; Lisa Green, The Salvation Army; Tim Brooks, GAC; Jamie Doan, GAC, Frann Anderson, DDDS; Barbara Monaghan, Citizen; Lisa Elias, Citizen, Micki Edelsohn, Citizen, Kimberly Reinagel-Nietubicz, Observer OCG

And I'm not sure how much longer she's going to be able to live with us, and I'm hoping that there is someplace safe for her to move to long before I keel over, I guess. So, the agenda, I put together with Tim's help, I read through all the documentation, and I'm no expert on any of this. I am learning as we go. The agenda was just my best attempt at trying to formalize, put some formality around for this meeting.

I'm Kathy Cherry with the Governor's advisory Council for exceptional citizens. I am also the parent of a young adult with autism who just this past year moved into an assisted apartment setting. A neighborhood home, they call them now. And he, too, had some aggressive behaviors that we were trying to get a hold of, and we did. Fear and medication. And I helped get that under control, and we are trying to get things set bankrupt for him, because we are not going to be here forever. So we want to make sure that we can be a part of the process before it's all him. So that's why we went ahead and started with the residential placement.

My name is Melinda South, and I'm from Bancroft. I am here for 2 reasons. One, I have about 14 years experience working with residential providers in Delaware, so I feel that I have the experience and bring a lot to the table with this group as well as it being a current provider and representing residential providers mostly in northern Wilmington.
I'm Lisa Greene. I'm the director of salvation army residential services in Sussex County, Southern Delaware. I've been with Salvation Army 22 years, a very long time. I am also a provider for Delaware so hopefully we can get some knowledgebase.

I'm Micki Edelson, and I'm the mother of a soon to be 43-year-old man, who is in a group home run by, well, it's owned by the ARC of Delaware, but the agency is Bancroft that provides the services for him. I'm not officially on this committee, but because I been involved in building group homes in New Castle Counties for 25 years, I want to see what is going to be the future of housing.

I am Fran Anderson with DDDS, and I'm the director of OQI, the office of quality improvement and I am here to assist the group in anything you need from DDDS and also as a resource if you need me.

My name is Brian Freedman. I am from the University of Delaware, Center for disability studies, I am not formally a part of the work group. My colleague, Victor Schaffner is. However, he wasn't able to be here today, so he asked me to sit in. The center has been

involved in a number of different issues regarding adults with disabilities. Including policies as they pertain to residential services. In addition, we, the contractor conducts the national court indicator survey, part of which is talking with DDDS clients about their experiences in residential settings.

We are introducing ourselves.

I am Kimberly Reinagel-Nietubicz of the Controller General's office.

I'm Tim Brooks. I'm here on behalf of the Governor's Advisory Council because we are sort of charged with helping out as much as we can in this whole process, so I see my job, and Jean as well, trying to support the group, in particular Libby, and to be a resource in any way we can. I won't claim to know the material any better than Libby. I'm reading it for the first time, too. I do have a son in the system, he just turned 50 two weeks ago, which absolutely is a shocker for me. (laughter) I'm really not that old, I want you to know. I did adopt him, as a little 5-year-old, although I turn 70 next, (laughter). In any event, Ross has what I call the big three. And as I listened to you, but he has pretty severe physical disability, massive hematoma, right side of the brain, right down the left side, blind in his right eye, and then his left side, it's like a (loud beep), I'd say a somewhat mild stroke. He has all sorts of artistic type behaviors even though he is not autistic in the classic sense of the term. Rocking, yelling, screaming, you name it. And biting, hand biting is a classic. And he functions that about a 40 to 45, 50 IQ. He is a wonderful guy. He's got some tough issues. As people have had as well. So my concern from a personal standpoint, he's been in a residential system for over 20 years. His provider has been absolutely terrific. I have no complaints at all. And I would hope for every family in Delaware who wants to get a person into the residential system, that they get the kind of situation my son has had. So I am here to help those people, not myself.

I am Bill Monahan, Co-chair of the committee. I am with Delaware People First, non-profit, and I was asked to sit on the panel as a self advocate.

And then you were coerced into being a cochair.

I was forced into being the cochair because there was no other self advocates at the last meeting (laughter). A helicopter landing at the White House, landing that thing in Washington yesterday, standing waiting for a sensible taxi and 5 minutes before, after we get picked up, the helicopter landed in the west side of the capitol, and the president was in the capital, so we almost got left behind by a trained because they were going to close all the streets, so the guy took the shortcut—

And I'm here. (laughter)

Hi, I'm Caney Jones. I can't give an explanation about why I am here. I have been involved with disabilities for many years. As a child I was AI. I had 22 surgeries. I missed a month of

school every year of my life until I was 21. So I certainly was in the system, involved with a lot of different agencies, my 1st summer out of high school, I worked as a counselor at Easter Seals Camp Fairly# Manor. And if you know anything about Easter Seals, once they get you, they get you for life. So I served on many committees and boards. My occupation was special education. I was a special ed coordinator for 2 elementary schools. That is my background. And I've always been an advocate for everyone having a high quality of life.
My name is Barb Monahan. I am with Delaware peoples 1st and I am a self advocate.
I am Lisa Elias. I also advocate for my brother Eric who has been in a group home with Mosaic agency as an active volunteer and stuff, so I am just here as an observer guest.

What is your name, honey?

Oh, I said Lisa Elias. Did I forget my name?
No. (laughter)

I'm Kyle Hodges. I am with the State Council for persons with disabilities and, by the code, with certain responsibilities I want to look into laws, regulations, programs and policies which impact people with disabilities, housing for people with disabilities is always a priority for us. So this issue of priority, I want to be involved.

My name's Laura Water (inaudible), I'm a staff attorney with the disabilities law program, community legal aid. And we have, my interests actually are similar to Kyle's, I would say. We represent adults in communities and facilities and also in the community and we are always looking to make sure that the individuals who need services are getting them, the ones that they are entitled to, and it is done properly, so kind of a legal perspective on it all.
Terry Olson. I am with the ark of Delaware. Previously worked in residential services for 35 years.

We meet in this room an awful lot. If we keep the doors closed, it's going to get 100 degrees.
Yeah, I was looking for--
Is it okay if I open the doors because--
Well, the people outside closed them.
Yeah, it was the secretary that came--
Yeah, they wanted to give us privacy.
We need the ventilation. It is so hot in here.

All right. Next is the meeting ground rules, just to review this information again. And I want to start by saying that the meeting is being recorded. Hopefully it is on and working her right here. So when you speak, please say your name 1st and make sure you are speaking up so you can be recorded. One person talks at a time. Limit phone calls. We will start and end on time. Try to stay on agenda. And hopefully everybody did their homework before this meeting to read through all of those wonderful documents. Let's see. I was wondering if documents are being sent through email agendas and those types of things, if people

could bring their own copies instead of printing out more copies.
Certain people can, probably certain people can't.

Okay. And then—

I should be getting them, but I'm not.

You're not?

I got the one last night, but I didn't get the agenda. I got this from Tim, but I didn't get the agenda.

Okay, I will check.

This is your right email address?
I'm using the same email.
William.Monaghan, monaghan35@verizon.

Yeah, I got one thing from you, but I didn't get the agenda.

Okay, sorry about that. I'll double check it. The other item I thought maybe we should talk about underground rules is, is guests are allowed to attend this meeting as well, and I have no problem if they participate as long as they read all the documentation, but that's just my own opinion, so I don't know if anybody else has an opinion on that.
I certainly don't have any uncomfortable with that. I think if something comes to a vote, then it's just the members.

Right. And does anybody have any other ground rules they'd like to talk about? Okay.
Let's move on to, I thought maybe we could just review the objective of this committee, if Tim just wanted to talk about that a little bit.

Yeah, I don't know if everyone got a timeline sent out to them. Did you all get caught very definitely the key element to start with is the development of the self-assessment, and Jane Gallivan talk about this at the meeting last time, last week, and that's going to be up to this group to put together something like you saw from Tennessee or from South Dakota. And both of those, as I look through those, had some very good points, and I think I brought Libby about questions in those documents are going to bother people in certain ways. Like, as I read read through them, I was ticking off, hm, my son can't do that, my son can't do that, my son can't do that. And I mentioned the keys issue. If we gave my son a key to his apartment and a key to his room, we would see those keys for one day, and then they would be gone somewhere. So I think we, I have to sort of apply that and analyze what is the value of that question overall for the population overall. And I think that's what we've got to do all the way through that. But we as a group may see some questions that we just think are inappropriate for the self-assessment. The other think that's maybe even more

important than that is what these other self assessments have left out. So that's why reading the initial documents, which Libby just mentioned she had done all the reading, well one of those is the home and community based waiver tool. That one has the actual questions in it, and if you look at those, and I think they begin on page 7--
Which document?
Let me pull it.
It's one that was on the agenda.
HCBS basic elementary review tool.
Yes, here it is. It is the HCBS 86 element review tool for statewide transition plans, version 1. And then if you look on page 7, just as a for instance here, that's where the question starts down towards the bottom.
7 and 9.
(pages shuffling)
Yeah, it actually starts under systemic process on 7. And to then it continues on for several pages, as those, if you look at this document at the same time you are looking at Tennessee and South Dakota --
It's the same exact--
They pop up all over--
Absolutely.

So I think that's part of our job, though, to look at those all over again. And get a sense for what we think is appropriate to include in a self-assessment. Now once this group has done that, then everything we do goes to Fran or whoever is going to replace Fran. What Fran didn't tell you was she's got a medical issue coming up in a couple weeks. So she is going to have to disappear, but I think DDS is going to get us some--
Yeah, we'll get somebody else.

Okay. Whatever this group decides to go to DDDS, and then DDDS looks at it, and then DMMA looks at it . So everybody gets a chance to review the document, but timewise, it has to be done by 15 June because that give the providers hopefully enough time to then go out to their various facilities and programs with this self-assessment. I did ask Jane Gallivan this week if this means a provider has to be a self-assessment on every residential unit, like a group home or a CLA or whatever. The answer was yes. So that is a lot of work for some providers who have a lot of housing. And that's why we're giving them until September 30 to complete that. Now, after that, every location—

This came up at--
This is Kyle.
This is Kyle, sorry.
Kyle, you're right. If every caught let's say we've got provider A, and they have 20 group homes. They have to do an assessment on each home.
This is Terry. Is that also true for shared living?
That is true for shared living.
There will be an assessment of every shared living site.

Correct.

This is Laura. Who is going to conduct those, DDDS, because there is no, they are not based with providers.

No, it will be a self assessment by the person who is running the shared living unit.
And I believe that's –

Just like Chimes would be doing their assessment on Chimes homes.

There's an oversight in that. I mean—

This is Libby. Last week Jean mentioned that it would be living there that would complete the assessment, but we can, can we you follow up with that?

This is Lisa. I guess is going to come when we get to the evidence, that is going to prove, because we are under certain guidelines. We have to prove all the time to the state because they are in our program, whereas shared living doesn't, so, I'm into the evidence-based is how are they going to prove those things.

Okay, so this is Libby. Fran is going to take that back to get the answer for us.
This is Tim again. One of the things that Jane said when she introduced this item last time was that she would like, and Fran, help me out here if I'm jumping off the wrong cliff, but she would like a way for the providers to document evidence, and I noticed in a Tennessee document that they had a column for backup. I didn't notice that in the South Dakota document. So in other words, if provider A is saying, this house serves people with medical issues, then there should be some document that backs that up.

Tim, let me, I'm going to put you on pause for a minute there. If we could get back to the agenda, we want to just go through the census data next, because you're starting to get into the assessment discussion on responses and those types of things.

Can I touch on one?
Sure.

Look behind is the next timeline here. And I asked Jane a few minutes ago who is going to do that, and we don't know. It could be members of this group. It could be somebody else. It could be people assigned by DMMA. Don't know. So that an unknown at this point. Okay. Okay. Next on the agenda, I was asking Tim a couple questions, and I thought it might be important that we understand who is going to be completing this assessment, so I asked him to just pull some statistical data together. Do you have that?

Yeah. Tim again. What I pulled together for Libby on an email was from a November DDDS census. DDDS is now doing these quarterly. This one came out today. So I thought we

should just run down the numbers really quickly here so that everybody has a sense of where people live in the system, if you will. These are from DDDS now. If you look at the top, institutional placements, that Marianne Coverdale center, I assume most of you know, it's the new building down there, and there are 54 people currently living there. Nursing homes, we have 2 people in psychiatric placement. I'm not sure where those people are.

They could be in the psychiatric center, I'm not sure, so I can't answer that for you. Nursing homes, you can see that for yourself. 50 in Newcastle, 7 and 7 in Sussex, one is out-of-state. The next group is the one I think Libby was most interested in. Residential placements. Neighborhood group homes and CLA's. And I think you all know what CLA's are. They are apartments. My son lives in one. He has one room.

Community living arrangements.

Right. So the total therefore the whole state is 860. As you can see, most of those folks live in Newcastle, 563. 139, 158 Sussex. Shared living is what we all use to call foster care. And you can see those numbers significantly less, obviously 127 total, and is spread kind of interestingly in all 3 counties, Sussex having the most. I believe that's probably because when people left Stockley, they ended up staying down there, primarily it was staff members in shared living arrangements. Supported living, Frank, help me out here. I understand supports. People are very high functioning.

Less than 40 hours a week.
Yeah.
Service.

And then out-of-state, 14. And some of those are very very complicated people, but I know DDDS is looking at that group to see who can be brought back into the state. They are very expensive.

This is Libby. Did Jane say that these people will be included in this assessment? The out-of-state?

I didn't ask that question. I would assume so.

This is Terry. I was just going to say, I believe our agreement with the state to build 2 medical homes include some of those out-of-state folks. I don't know how many.
I'll get a definitive. I just ran a definitive. Definitive answer from Jane.
Okay. Do we know if they are in group homes?

Some are in placements that they need to leave, and it's because they are no longer providers for DDDS. Others, I think, would stay where they are, whether or not they need to meet our assessment needs here in Delaware is still a question . They may have to meet the needs of the state that they are residing in. But I will get a definite answer from Jane.

Okay. ETLA emergency temporary living arrangements. Those are the folks who are in crisis. A parent may have died, a person becomes homeless, caregiver may become so ill that they can't take care of the individual any longer. And just as an aside, there are 13 of those folks right now. We have had a huge influx in that category this year. And because of that, when you look at who gets placed when, they always go to the top. So the emergency placements in residential this year are primarily this kind of folks. Jane explained that to us at the last of Governor's advisory Council. So that's pretty much the census total. I have been on the Council for 28 years. There are now 4063 people in the system. There were about 2200 when I came . So this census grows every quarter.

Tim, this is Libby. The family support, those are people living at home receiving services? Yeah, and that's a huge number, 2888.

This is Terry. I think, correct me if I'm wrong, Tim. Jane has characterized those persons as barely served in most cases.

Correct.

This is Laura. These are not people to be on the Medicaid waiver.

No.
Right.
Is Melinda. But I think it's important to when we are talking about saturation that those are people who probably will at some point enter into our services, so we can see, that's a large addition to our population.

This is Tim again. I am going to slip one in on you. I was also asked to find out how many total group homes there were. Again, I've been around a long time, and I've never seen this number before. It's 183. I got this number about an hour ago, and the number of supervised apartments is 145. And the total number of shared living is 130. That does not compute with the number we have on this sheet.

One more time on the supported living.
This is Fran. This is from February, so March is numbers are not completed yet. We've had some new homes open in the last 2 months.

The numbers again. Group homes, 183. CLA's, 145. Shared living, 130.
Does anybody have any questions on this before we move on? Okay. So what seemed to make sense to me, and this was 2 days ago, and I'm not sure it still makes sense, within Delaware's plan it says that we need to utilize the questions in the overall. This tool is the questionnaire I believe it was referring to? There is another questionnaire that was distributed, and I believe it's the same questions from CMS. So I thought maybe we could start by reviewing the questions in this document. It's the HCBS basic element review tool for statewide transition plans, version 1.0. And as Tim mentioned, it really starts on page 7.

Under number 3, I believe. So I don't, and this is open for discussion . But I don't believe that we need to say we are going to include number 4 and not number 7 at this time. I think if we can just kind of review the questionnaires that we've been provided to date and maybe wait another week or 2 to see what other questionnaires are available that have been approved, and then at that point we will start narrowing down what the specific questions are going to be for Delaware. Just a thought. One other, I had a question about , it seems that Delaware's plan does not have any more specific requirements than the overall CMS requirements, is that true?

Yes.

Okay. So looking at this document it is a good idea then. What I have noticed through several of the assessments that we've seen so far is that the questions seem to be somewhat the same, but the response options kind of the very, and personally for me, I kind of liked response options here , but that's going to be open for discussion as we go along, and I guess the other question I had before we get started, Tim mentioned what documentation is it going to be required as evidence of the following the rule or as they go through the questionnaire, if they say yes, are they going to have to provide some kind of documentation or know what documents they have. I don't know if anybody knows the answer to that , or maybe friend, you can take that.

Sure.

All right , anybody have any other thoughts before we start looking at this? Okay. So I guess we will just go through the questions and throw out any thoughts or concerns as we go. Number 1, does the state include detailed description of systematic assessment of whether its standards comply with the federal HCB setting regulations . And I think these are more state-level questions, which I thought the specific questions were really started on page 9. So if everybody, does anybody see any specific questions we would want to review before page 9, on page 7 or 8?

This is Kyle. And who is going to complete 7 and 8, will that be DDDS or?

Yes, well, this document is a document that each state has to complete every turn. DMMA, feedback was it was sufficient.

So we'll start on page 9. And I think whoever's transcribing can figure out who I am by this point. I am Libby. Number 3, A. The setting insures an individual's rights of privacy, dignity, respect, and freedom from coercion and restraint. The responses yes, partially explain and a evidence and no.

This is Terry. I know someone mentioned is that they believe that these questions are very straightforward. I guess I would disagree in the sense that interpreting these questions is going to be an extremely difficult and, from my perspective, they are very ambiguous

questions. I think that it is going to be necessary to include what I would call groups, which would be individual questions which delineate aspects of the overall question, and then some mechanism for translating that into a guess, no, or partial as far as compliance, but that's just my opinion. I think as we go through these, we'll see more and more of that. By the way, I also think that most of these criteria are at least echoed, if they weren't in fact drawn from CQL, Council of Quality and Leadership, and I went through a certification process with them for a number of years. They have probes, which is the reason I mentioned that. So that might be a source to consider.

This is Gary. Would you explain CQL?

The Council of Quality and Leadership is independent accreditation international agency. CARF is another similar type accreditation agency. CQL is known for being a progressive and pretty demanding with its standards.

This is Kyle, so, Terry, are you saying that in general throughout this document that the questions are ambiguous?

Many of them are just a totally ambiguous, absolutely.

I'm just trying to get a sense of generally what you and other people are thinking. Do you think that, this is Kyle, they are not consistent with the guidance from CMS?

I think they are, but I think the guidance from CMS is extremely vague and ambiguous as well.

And I think he is saying how are we giving these tools to the provider. Are we going to give them this tool to do, or are we going to give them these probing questions, are we going to have a training with them 1st? I mean, there's a, I hear what you're saying.

This is Terry again. I mean if you look at that 1st question, rights of privacy, dignity, respect, freedom from coercion, I mean you could have 150 probes on that one alone, and still not cover all the bases. Now, I am not suggesting that we do that but I am suggesting you are going to have to have some probes and some mechanisms for establishing that, because the question is too broad as it is.

This is Libby. Terry, is that the document that you could share with us?
Unfortunately, that was at Mosaic and I don't believe I still have it. But I will try to track it down.

This is Gary. Terry, probes, could you explain that?

Sure, for example, a probe might say here, does the probe for rights of privacy, does the person have the right to meet with the person of their choice in a private room without

anyone else present. For freedom from coercion and restraint, obviously, does the person had any restrictions with respect to access to the home, for example, and that's probably not a good fit for that particular one, but, dignity and respect schedule really kind of nuanced, as you might imagine.

This is Kathy, I have a question. We are looking at the ACBS tool, but if you are looking at the one from South Dakota, haven't they kind of broken it out into those kinds of probing questions because I was looking at can you lock your bedroom door, can you invite people over.

This would be probes, absolutely. I apologize.

Okay, so when they did the actual questionnaire, they brought those things in. There is even one about, are you treated the way you want to be treated which, would lead you to answer about, of course. Things of that nature.

This would be good examples of probes.

The ACBS staff assessment individual assessment.

That's tough.

Gary, could you introduce yourself, to be recorded?

I'm sorry, Gary Mears, representing the Developmental Disability Council.
Kathy again. I thought what we were supposed to do was look at what ACBS is saying, you need to ask these questions. And then look at the examples that we have from other states and see if they actually ask them, and if we want to duplicate those kinds of questions here in Delaware.

This is Libby. I took this document as a starting point for a questionnaire and then, as we saw in some of the other state documents, they have more specific questions. So I think if not all, some of us agree they are too general and will need to be more specific in the questions. What do people think about the responses? And particularly, if this is all about person centered planning, if you have a group home up for or whatever number of people in a group home, how do you answer some of these questions when you are talking about 4 people, who are very different.

This is Tim. I think that the self-directed plan is critical here. When I look at these questions, the evidence line is one where if I were a provider looking at a group home and person X is there, I would want to know that some of this is documented in the ELP. And I understand from Jane we are redoing the ELP right now. And I'm not sure how that's going to turn out, but that becomes incredibly important to the provider that whatever they answer in general, it can be picked out. That's why I like the South Dakota question. That

you can pick out some of that stuff that's right in the ELP. Especially the questions about community. In the ELP, it says person X is supposed to go into the community twice a week or something. And you can pick that right out, so that's evidence that the person meets that particular question.

This is Lisa. I was just thinking about (inaudible). My brothers agency. That's Lisa Elias. He participates in the community, is always documented as well as other things, but that would be one place to go, to that agency.

Sorry, I didn't quite hear that. What was that called again? This is Gary.

Therapp notes. T-h-e-r-a pnotes.

Electronic record keeping?

Yeah.

This is Lisa. For the purpose of the ELP, the state case managers are responsible for writing the ELP's, which is different now, so if we are using that, it should be all included in the ELP's and you would think that we would be working together, but as far as the assessment tool, we don't want that to be maybe necessarily the point that we go to prove that we are not responsible for writing that tool.

This is Terry. I mean from a provider's perspective, the client record, in this case, Therap, is generally considered to be the primary source for documentation compliance with all person centered types of regulations. So, when it's as evidence, and I've already asked this question, but I'm not sure when this was sent out, are we going to be asking agencies just to write down what the document, person X's ELP is the evidence of that, or are they going to have to actually submit that as evidence? Because there's going to be a lot of documents that will have to be collected.

This is Fran. So I think there's several ways to do it, and this group can make a decision about it. One way is to ask the provider to tell us what they're using as evidence, so if their response to a question is, yes, we do this, then that may also say as evidenced by, and tell us that they can present. Another way to go is to determine that we want the evidence to be uniform, so we wanted to come out of Therap, but we want to see it in a written policy. Or if there's a policy that in some way doesn't encompass everything, we want to see the old policy, and the new policy. So I think this group has some wiggle room in what exactly the evidence would be. So I guess some discussions around just exactly what you would feel comfortable looking at as the evidence to prove that whatever is being said as part of the assessment is accurate.

This is Terry. I guess another key question to be considering is what will we be expecting the providers to do in terms of their sample. And what will be looked behind people be

doing as well. I think that somebody mentioned you got 4 or 5 people in a group home, and you are looking at trying to find meaningful evidence of all these standards being met for each individual, you are looking at a pretty intimidating process. I know for CQL, the survey process generally consisted of somewhat, what's the word, samples. Random samples. But in some cases they would ask for a specific issue, like a person that's on a behavior management program person that's on a psychotropic medication, so on and so forth, so they can get into some of the specifics, but, those are going to be key questions.

This is Tim. Jane made it pretty clear to me that every unit is going to have to be looked at. Does that mean every person?

Yeah. I'm not saying they're doing a total.

Are you saying every unit? Or every person in the—

Well, what she said was every unit, but I think it's one and the same. I don't know how—

So there are going to be different answers for different people, like I looked on some of these questions, somebody in one of my people is not going to have access to the telephone without us supervising because of reasons for her, you know what I mean? So it's not going to be the same for that person in the house.

Yeah, absolutely. Yeah, I keep thinking about my son.

Right, right.

Yes, I guess that gets back to the question Ms. Libby asked earlier, I mean if it's a group home or 4 people, how do you answer, how do you complete this questionnaire? When it's person centered, you can't just say—

Important question.

I mean some facility ones are easy, is it in a neighborhood, is it blended with other communities? I mean some of those are pretty basic but when it gets down to the other—

This is Tim again. One thing. As I'm listening, I'm worrying from the providers' end. Terry talked about the probes, and I think that's what South Dakota was trying to do. They kept it simple. And I think that's our job. We got to keep it simple. If the provider has 24 units out there, and there are 4 people in each unit, holy smokes, that's a ton of work. The simpler we can develop this self-assessment, the better off we are and the provider.

This is Kyle. Tennessee also is pretty specific with some of their question. There's more of them . It breaks it down to individuals, Community integration, Physical location, Resident rights, Living arrangements. I think it's a decent one also.

This is Fran. Just a suggestion. You want to kind of think about the tool as being process oriented. Versus individual in it. So you may, as a process, provide everyone with the opportunity to use the phone unless, there's something else that happens, so that would capture those folks who maybe don't fall into that category of having access to a phone or someone who can't do something alone because they need somebody with them all the time. But process wise, the facility may very well have processes that promote that unless something else doesn't they can't do that.

This is Libby. I don't know if that's what the partially checkmark means, and if it's partially, and they explain what's 2 people are yes and 2 people are partial, and they have ELP's that specifically address that issue. Then I would assume that partially and yes are equally scored, if there was a score for this. So maybe that's how it would be handled. So, should we just keep going through these questions and kind of, if you have any comments, just speak up. The 2nd one, the setting optimizes individual initiative, autonomy, and independence in making life choices.

This is Terry. That about as ambiguous as it gets.

Yep.

Could write a book on that and still not for any individual.

I would agree.

This is Gary. I mean, the only way, I look at evidence as kind of going from objective evidence, where you can count numbers, hours, dollars, discrete entities, to more difficult to define concepts like autonomy and independence. And when you have those kinds of terms that are more ambiguous, usually the group has to agree on what it does mean. You operationally define it as best as you can. So the questions that are going to be a little more objective are going to be a lot easier to make your choices on versus these more difficult concepts, and again, we don't have a lot of time and we want to make it as simple as possible, so we can all agree on those terms, what they might mean, or if other states have given us some guidance, maybe. With those probes that Terry was talking about, that would be a heck of a lot easier on everyone, I guess.
This is Libby. So maybe as we go through, many of these are ambiguous. And then they start getting a little bit more focused. But we should keep that in mind, and as we are looking at the other states assessments, some of them to get a little bit more focused on their question.

This is Kathy. I was thinking maybe instead of just going through the ACBS document, maybe go through it and compared to the ones we have here to see if the pick up those questions, because I think what we are going to find is if you look at the vague question on the a CBS, you are going to find it broken out more on the 2 states that we had to compare.

So instead of just saying, well is this vague, or is this to generic, if we can find a comparison question already broken out, that's going to help us more. Because that way you are not saying this is too vague, we need to expand here. Next one, this is too vague, we need to expand here.

This is Terry. Are they in the same order, something that's reasonably done?
Doesn't look like they are too much in the same order. But we do have the staff assessment from South Dakota and the Tennessee resident letter.

This is Melinda. I agree with what you're saying. I think if we go through this and kind of find that question in these probes that they already have defined, we might be able to match them up and decide for ourselves if we feel it fully answers that question.
I agree, but I'm not sure how much time that's going to take to try to cross-reference. If we can do that during this meeting, maybe if we just finished going through this document and just know that there are some vague questions. I think that would be good assignment. Match them up.

In this document, I think it's on page 13, the questions, and then there is a 2nd set of questions which are exactly the same as the set in the same document, so we don't need to go through that. But why don't we just quickly go through this, and then move on to South Dakota, if that's okay. And then, as homework, we can kind of cross-reference the questions. To take the state questions back and map them back to this. If that's okay.
This is Tim. I think what we might find is at some point, these questions aren't applicable. Like C is a real question mark in my mind. And D I don't think is appropriate. The setting facilitates individual choice regarding services and supports. But it's a hard one for me to understand. I'm trying to think of how our group homes work. I'm not sure what they mean by services and supports. If they mean PT, OT, speech therapy, that kind of stuff, I don't think people are getting that in their residential location.

I think it goes back to what Gary was saying before. If you're going to look at these, you got to define everything. Which can get difficult in itself.

I don't think in general that question is necessarily bad. It's how you define things and how you want to get to probes, whatever you want to call them, get to that point.

This is Terry. One example of a probe there is, is there documentation that the person has chosen to live where they are living.
This is Kyle. And I saw in some other places, they actually asked that question.
When I read this question, this is Libby, I thought it was more related to the agency selection. So, again, it goes back to defining what you mean by—

This is Tim. D, I don't see where that comes in unless the setting provides opportunity to seek employment at work and competitive, integrated settings, that's a day out question to me. Am I off base here?

I think we can leave D out of the conversation.

If you're looking at, this is Terry, personal resources, typically the questions you're looking at are finances, unrestricted accesses to, access to personal belongings, so there is some applicability there.

And the community life also is not work based.

Yeah, that's true.

Yes, this is Kyle. Just not the employment. Number 4 is about a lot of different, or D Is a lot different questions combined into one.
Right, okay. So ambiguous.

E, the setting is integrated and supports access to the greater community.

This is Kyle. It is similar to the part of the question about community integration.
And how do you define integrated?

That's one of those terms, this is Gary, that you have to all agree on and go from there. Totally subjective without criteria. The setting provides opportunities to engage in community life.

This is Laura. Are these things what the state has to refer to based on the results of the self assessments that they are going to conduct with individualized questions?
Um hm.

So it's really not, these are not the questions that are going to be asked. These are the questions that the state is going to answer.

These are the questions that the state needs to answer and send back to –

But we have to come up with the questions and this is just a starting point.
That is South Dakota.

All right, so do we want to finish going through this quickly or just move on to South Dakota?

I think it's worth going through personally.

I mean we have a couple minutes.

I think Kyle is right on target.

E, F, G are all part of that previous question. This is just breaking it out.
And then H. Opportunity to receive services in the community to the same degree of access as individuals not receiving Medicaid HCBS.

This is Terry. If a person has a disability and if they have any vulnerability, the answer to that is always going to be no. Almost 100 percent of the time I would say if a person is in services they are going to have some restrictions on those types of issues, but that is just an opinion.

This is Tim, why. I don't understand at all.

Well, opportunity to receive services in the community. I guess the question to ask is does the person come and go as they choose the 24 hours a day.

This is Tim. That is not the way I read it at all. Again I keep thinking about my son so bear with me. I just went to his psychiatric appointment with him and that is the way I read that. Services, I guess there is a later one that I was thinking of, sorry.

This is Kyle, I would agree with Tim's assessment.

This is Libby. How did he get there, is that the same way a person without HCBS would get there?

Yeah, I took him (chuckling).

How many 50-year-olds have their dad taking them to their appointments?

I don't know (chuckling).

The ones who can't drive.

My fault, I was looking at a later criteria, sorry.

The setting is selected by the individual from among options including non-disability specific settings in a private unit and a residential setting.

This is Tim again. I think, when I was looking at these, this one really jumped out at me. I am going to break my rule again, Libby. I think about my son all the time when I look at these questions. He has never had a choice about where he lived, but it has always worked out, so I am not sure if I were a provider, how I would answer that that.

Well, I think the older providers are going to have a harder time answering that. I think that maybe from 5 years ago forward, have choices. People have had choices, but those of us who have had people in our services for a very long time, they didn't have, and it has

worked out. So there hasn't been a shift, but we can't necessarily show that the people we've had for a very long time have had the choice.

This is Kyle. It's about not what hasn't happened in the past, but what is going to be happening now and to the future.

This is Melinda. I want to say one thing about that too. I think the state, what they have done towards this, and we should look at that as well, is give individual's choice. It is structured choice. So if you want to to come move in with me, I have these 2 homes open, choice to be with any provider, any clinician, choose any nurse that you would like. And I think that that is how the state is trying to set up the choice. Occasionally people choose to move into apartments rather than a group home or to live in other settings. I don't think we are that far off of it even though it is more structured choice than hey, I want to choose to live over here where (inaudible).

This is Terry. I think a lot of that documentation is probably going to need to go in team minutes and I think one way to address a lot of these issues would have a set of issues that provider and a team need to go through in the course of an (inaudible). The other thing I think this brings up, of course, is guardianship, where I think for Tim's son, and I don't know if you are the legal guardian, it the 1st to the Guardian. But we have many nonverbal persons with no guardian, so it does become complicated.
This is Tim. That brings up a huge point for me that in all of this material I didn't see anything about guardians.

It's probably a good thing, because the state wouldn't have been able to respond to it. That's a whole issue that is –

This is Lisa Elias again. I am my brother's legal guardian I have one thing that occurs to me, too, is the needs that change over time. He did ask years, years prior to being placed in a group home to move into a group home. That was his choice. And since then, he's been offered some choices that weren't appropriate. And his mental status has changed as he ages. But that guardianship isn't anywhere in here.

This is Kathy again. Along your point about his choice at one point and then inappropriate choices later, and things changing, the levels of ability are also going to be different from one person to another, and to those are going to change over time. Like my son didn't necessarily choose when he went into it, but he did, he was a part of the discussion, even though we are his legal guardians, we make sure that he is a part of everything that surrounds him. But had we not found the right combination of things to work for him, we were in a position to go ahead and make those decisions for him. So as his competence level changes, things have to change, and that should be notated in here somewhere, too.

This is Fran. So if we start to look at this from a process perspective, it's possible that agencies started this 3 years ago, and there's no documentation of that, so the evidence is

we now need to policies saying we do this. The evidence is as of today, this is our policy. But it could be we, yes we do this, because we meet with guardians and discuss with the Guardian, and to make decisions based on information we gather, or yes we do offer choice except when limitations are such as this.

These will be delineated out.

And then the agencies, kind of, job to explain how they do it, if they are not doing it to the extent that it needs to be defined or identified for the purposes of this, how are we going to make that clear.

Just an aside for a minute. The recording is going to be transcribed within how many days and sent out to us?

I'll check with Vicky, but we should be able to have it done by the next meeting.

So we should all receive the minutes from this meeting. For the next meeting. So what are we on, J? If provider owned or controlled the setting provides a specific unit dwelling that is owned, rented or occupied under a legally enforceable, I didn't really understand these, if provider owned or controlled, that's versus what.

My understanding is that in a group home is going to meet that criteria. When you get into the CLA's that might be a little bit more ambiguous.

So apartments?

Yeah.

Versus apartment? Okay.

For example, at our supervised living arrangements that I get the 2 mixed up. Is CLA less than 20, or less than 40 hours?

CLA is exactly the same as neighborhood homes. The only difference is they are not a standalone home.

Okay. It's the CLAs that are –

It's the drop in supports that are different.

And that's supported living arrangement.

Right. For example, in the SLA that that we operate, which was a gift from homes for life, the individuals had to sign the lease.

This is Micki, but also in the provider owned or controlled, now The ARC is a landlord--
We don't control.
Yes, but the providers are leasing from The ARC. That's different. But we do have providers that own and operate. That's another different thing.

This is Terry. For every group home or CLA I think that it's going to meet that criteria from what I get. The other questions that come up is what specifically are we going to expect. A lease is legally enforceable, for example it does not say who. It's legally enforceable, but does that in any way benefit the individual? Some of these later questions get into that, but that's a very vague criteria.

This is Laura. My understanding is that there is going to be some sort of enforceable agreement that benefits the resident.

That would make the most sense.

Where are not really talking about the providers lease with its landlord, but it's the residence relationship with whoever is running the home.

That was my assumption.

Or I think it would be particularly beneficial to people in shared living arrangements because if it goes down that far because (inaudible) protection whatsoever. Even if it's not called a lease, it has the elements of the lease in terms of notice, you have to have cause, and all these kinds of procedural protections that residents have been regular commercial landlord tenant relationship, so I think it's really they are contemplating the agreement between the resident and provider.

Okay. This is Libby. Several of these following questions seem like they would all persons in any type of homes. So what does it say if provider owned or operated.

My understanding is these particular things, these particular requirements are specific to provider owned group facilities. So actually it wouldn't apply to facilities, now that I think about it.

But why wouldn't it?

If they meet the definition of provider, then yes.

I mean to have a locked entrance to your bedroom door, wouldn't that--
These are requirements that are specific to this is what they are basing it on. This is regulatory requirements for home and community settings document. It has these general requirements, and then it has these specific additional conditions if there is a provider owned or controlled residential setting. And that's when you get into all these other--

But the assessment is for group homes, community living arrangements, shared living arrangements, and supported living arrangements.

Right.

So why would only the provider owned or controlled--
Well, I think these are just residential settings, not the day programs, right?
Right. But if a supported living arrangement, one with the drop in care, why wouldn't they have to have probably these same requirements for lockable entrance and all that?
I think is conceivable, this is Terry again, that a person might wreck their own place and have control over it. In other systems where I have provided services in other states, that's been the case. I am not sure about Delaware.

This is Terry again. I think the other thing to do, and Laura you might be able to help us with that, is we need to abstain state, county and city tenant laws since were going to have to--
There's a state.
They are all under the state.
(People talking simultaneously)
Would you be able to get that?
Yeah.
Okay. Would you be able to get those?
Oh, sure.

NOP, locked entrance doors, choice of roommates, freedom to furnish and decorate.

Can I step back, this is Terry again. One of the concerns that I wanted to raise here, and I think any provider and certainly DDDS people are aware of this, is there is a balance point in terms of tenant rights and the rights of other people that live in the home. And if these stakeholder, for example, is physically abusive towards peers, we don't want to create restrictions that put 4 people or 3 people at risk for a period of months while one person is enjoying the due process and other people are being tormented because of verbal or physical abuse. So it's not going to be an easy thing to balance out.

This is Brian. Can you just clarify, what are you seeing on here that you are worried?

I am back to K & L where it says to address eviction processes and appeals comparable to those provided under the jurisdiction of landlord tenant laws.

There is a forthwith emergency procedure under the landlord tenant code for evictions if there is a danger to others.

How expedient is that?

I don't know.

Well, if this criminal behavior you can always--
Well, that just doesn't happen in group homes, they don't want a police car--
I know, I know it plays out, but I mean, that's the other alternative you have.
Yeah.

This is Tim. You have to go to court to review that.
You can file a forthwith Summit and get an ex parte order to get somebody removed. But you are right, it's not like that. But on the other hand, maybe it should be. I don't know. It depends, if it's not, (inaudible) where his criminal behavior and the police need to be called, but it's kind of an in between area. There might be some alternatives. I mean, I am just thinking out loud.

This is Terry. I mean I have, again, did this for 35 years. Typically the police did come, they would throw up their hands or you're in a situation where if they do take them, then that person is at risk and those police are at risk as well, so be careful what you wish for.
It's a bad situation going worse.

Okay. Q. Setting provides individuals with the freedom and support, control their schedules, activities, and have access to do it in anytime. (laughter)

What was that?

They wish midnight, they'll be alone. (laughter)

For the most part, they all do, except for some restrictions, diabetics—

This is Terry. I think you're looking at the question of all food versus reasonable snacks. I mean are you going to have somebody getting up in the middle of the night and starting the rolls that was supposed to be for somebody's dinner.

This is Melinda. Or eating raw. So you have food safety issues, and on one of the probes they do address that. They said where appropriate.

Let's keep going. If provider owned settings allow individuals to have visitors at any time, setting is physically accessible to the individual.

That makes me so happy.

I have to say something out loud. (laughter)

13 at the top.

There is a huge shortage of accessible housing in Delaware. So this can prompt more--
I am thrilled about physical examples. But the problem there is--
Happy about S.

This is Terry. I think that number R is going to be extremely problematic considering routines, privacy, rights of others, it's easy to say, but I think if you've got somebody that's kind of barging into a home in the middle of the evening, most people are sitting around in their pajamas or nice robes or whatever and suggesting that people can have people, midnight, 1 PM, or 1 AM—

How often does that happen? I mean we have in our group policy people can come and see their families whenever they want. I mean if they call at 10 o'clock at night if they want to see their family member--
It's limited. But I think you're going to have some issues on occasion.

This is Melinda, and I agree. What we typically do in homes, and this can be where reasonable, we can probably put in that small little catch because they get together, they make their own rules for their home that they live right, that they don't want people coming in at 12 or 1 o'clock, so I think if we just push that, where reasonable, we should be covered.

That brings up another question, this is Terry, is the group going to be able to make up house rules that preempt these regulations. I'm not saying they shouldn't, I'm just saying--
You mean the group in the group home.

Yeah.

That's good question.

With regard to item S, physically accessible, I agree with that so completely that I can't emphasize that enough. But DDDS is behind, the Arc is behind. I think about 70% of our homes are only partially accessible, if that. So there's going to be a lot of no's on that, and I think strategically and in terms of long term types of planning, it's a huge huge need that needs to be addressed.

This is Libby. You said that specific to the individual, so the individuals living in a group home, it's not physically accessible. Or is this in general for people that don't have physical requirements?

Well I guess there's two ways of looking at that. I guess for the individuals that live there, which in most cases meets the requirement, problem is most of those individuals eventually if they live long enough or are lucky to live long enough, are going to require physically accessible and that is where they end up in nursing homes where bad things happen.

This is Brian. So just to clarify, so you are saying this makes sense to you to have it in there, to make sure that we—

It does. What I am saying is there is a huge deficit of physically accessible housing in the DDDS system.

All systems, not just DDDS.

Past our time.

All right, timekeeper. This is Melinda. On one of the probes it does say is the setting physically accessible, are there no obstructions such as steps, widths in doorways, narrow hallways, limited, that limited individual's mobility in a setting? So I am wondering if this is the difference between is it, what is the right word now, handicap accessible according to those building codes or is it accessible to anybody able to move into the house without--
This is Kyle. That was going to be my, you got physical accessibility is a very broad term, and who defines what physically accessible is. I would hope eventually you are striving for ADA accessibility.

But not every one of my homes is handicap accessible.
Right.

And the interesting thing on the flip side, and we can talk about, and I know what he is talking about in the future, as people age out, they may have to move. But we have a challenge when we look for sites because of the fair market value of what the state is willing to pay, so you can't find handicap accessible sites for 2 people and 3 people for $900 and $1300.

This is Terry. But PM62 does have exceptions for accessibility kinds of--
But these people don't need that right now.

But there's problems, I understand, absolutely.

Okay, so we are going to move on to South Dakota, which hopefully will drive down some of these into more detailed questions and just as a good point to check, can you still make sure this is still recording?
Still good?
Um hm.

All right. So, South Dakota document. If you don't have a copy there are some extra copies here. Anybody need a copy? Start on page, circle number 2. They are not numbers, as far as I can tell. Second page, title HCBS settings provider required self assessment. Everybody has? Anybody else need copy?

I am wondering if it's worthwhile to number pages so we are on the same page.
So we are going to call living agreements page 4?

This would be page 1, right? (chuckling)

These all together.

Okay, so starting on page 2. And I think we all understand that we are going to need to come up with a page 1 summary at some point, but let's just go right into the questions. Number of individuals served in the facility. More detailed of a question. What living options are offered to individuals in your setting?

This is Tim. On number 2, I think we ought to have the other, the CLA's, I don't like grouping CLA's with group homes. Maybe that is just me. But I put CLA's in there and I put foster care or shared living, whatever we want to call it, also in there. I'm not sure quite what assisted living is. That looks to me like drop-in supports. I don't know.
This is Terry. Each state tends to have its own names for specific kinds of services, so that would be my suspicion.

Well, I think that is a worthwhile question and we will just map it back to the four letter defined in the state's, in our state's document, so that is group homes, community living arrangements, shared living arrangements, and supported living. Is the setting also a nursing facility. Any comments?

This is Tim. I think let's try to get at, I may be wrong here, but it may be something like the Stockley issue where there is a group home on a Stockley property. That may be what they are trying to get at.

Yeah. There is a whole thing in regulations where it talks about what does not constitute a community based setting, and these are the criteria, it will take you right out of the definition of a community based--
All right, actually number 4 is what I was thinking about.

I think 3 is, this is Terry, it's probably referring to a nursing home, and by way of clarification, some of the homes that we are currently working on constructing for DDDS are going to have nursing services, so you get into a semantics issue there.

This is physical license for facility.

If it says licensed nursing home, I think—

That's what they mean, I think—

This is Melinda. Terry, those homes which a lot of us call, support medically fragile, do they

have to have a separate licensing in a group home?

No. I'm just looking at the criteria and thinking it could cause confusion.

This is Fran. It's possible that some states do contract with nursing facilities as residences for some of their individuals that they support, so this might be something specific to South Dakota and something that Delaware wouldn't necessarily put in their assessment.

This is Tim. Fran, given that, is there any reason in our self assessment to include that, especially since they deal with, one I was thinking about—

Not as a provider. We do have some individuals in nursing facilities, but not in what we would consider to be like a residence that automatically take folks as part of a contract we have with them.

So based on this, this is Libby, the document that was handed out, we have 65 people in nursing homes in Delaware.

Will there be any kind of assessment for them?

Good question. I don't think we've, if that question has been answered, it was not when I was around. Let me ask again.
Are they all elderly?

I mean as a provider, I know that key criteria was if somebody needed fully accessible and/or nursing care, they are going to a nursing home regardless of age. Most of the time. Okay, it says setting on the grounds of or adjacent to an institution. I don't think there is any—

This is Kimberly. This is an f-y-i. We do have on the ground for an institution in Delaware because we have group homes in Stockley.

One other state. Currently we have CMS approval for those group homes to stay on that facility.

North Dakota.

Yeah.

South Dakota.

One of the big ones.

There is a process you have to go through.

Right. The state intervenes and requested for that to be allowed, someone else approved it. So-

I'm sorry. This is Gary.
(people talking at same time)

Absolutely. But I am just saying for consideration here, I don't know what the CMS is going to do.

This is Terry. We're building a home for the people, women currently in the group home on Stockley grounds. So I think that is the only one.

This is Fran. The plan is to move everyone who is not actually living in skilled nursing off the grounds of Stockley.

This is Tim. Do we still have that home with the Governor Bacon?

There is a facility at Governor Bacon.

No, there was a group home built there physically for sexual deviancy.
Oh, yes, mainstay. Yes.

So that would fall under this. I wonder what DDDS is going to—

Not getting Medicaid home and community based services.

It could be because they're adults.

I don't know if they're Medicaid or not.

I doubt it.

They're licensed by us. So there are individuals who do get home and community home services under the waiver, so--
Is it actually on the ground?
Yes.

So in this document, one of the documents that was distributed last week, it's a question and answer document, it says, are settings on grounds or ajacent to private institutions considered not to be home and community based, answer is, it depends. Settings that are on the grounds of or adjacent private institutions are not automatically presumed to have the characteristics of an institution, and then there's the whole process you need to go

through. Number 5, is the setting located amongst private residences and or retail businesses? And I guess my question on this one, this is Libby, would be, is it located amongst, does that mean located within 5 miles, within 5 blocks? So I think we would need to define that a little bit.

This is Tim. I think we could define that whatever way we want since they haven't defined it.

Yeah.

This is Fran. I might suggest that you might want to review the Olmstead ruling, because there may be some specifics on Olmstead. I know for the states DOJ, settlement for mental health bill, and you can't have more than 22% within a certain radius.
So as our legal person--
5 and 6 are related, right?

Right.

This is Todd. I think that DOJ agreement also, when you are talking group homes, I don't know if they're homes whether you can have more than 2.

The 2 and 20 rule. No more than 2, and then no more than 20% in like apartment complex. That would be number 6.

But that was, you are right, just that serious persistent mental illness does not apply to a group home, so, open for interpretation.

So that is number 5, and 6.

So how many people are allowed to be on the same (inaudible). I mean there are some agencies that have multiple apartments in different complexes.

There is also group homes that are side by side or real close.

Yeah, we just moved into a development where there is two other townhouses. They are not next to us, but they are in the complex somewhere.

This is Terry. I think one of the—

I don't know what you can do in the small state of (chuckling)

One of the key questions is, is each no here going to have to be remediated?
Again, we are not going to have yes or no, there is going to be some other options.
Yeah, but in the case of a no, for example, two side by side homes, is that going to have to be

remediated?

This is Tim. I think one way to handle that, is, I've thought about this one quite a bit, 'cause we have group homes side by side. I think one way you can handle that is by a policy statement saying, we have this in terrific, frankly, however in the future we will work to make sure we don't put them side by side.
This is Libby. But that is not a requirement of this CMS rules. Nowhere in the CMS rules does it say, only two, or you cannot have living units side by side, and there can only be two people in a group home. It doesn't say that anywhere in the regulations, or whatever the rules.

This is Micki. A ruling from the Attorney General in 1990, overturned, there is a statute that says you can have group homes side by side or across the street, so that is the Delaware law, that is allowed. That was overturned in 1990.

This is Gary. You are saying that that trumps CMS?

It does. If you don't want to take Medicaid, you can put your group home wherever you like. But CMS does not say you—

What all these questions are trying to get at is, is this a community based setting or not, and if it's not a community based setting, you can't get Medicaid, so these are relevant questions.

This is Fran. I think what we are missing is that we don't know what South Dakota's intent is once they get the answer to the questions and whether if they see that question, they are going to say okay, well, you are not in compliance with us. It's what our state wants to do.
This is Terry. I believe that Kim's point is very instructive here. In this case of North Dakota they were able to get an exception to have group homes on a campus. Delaware certainly should be able to get an exception to have existing group homes side by side, and I guess the question of future group homes remains open, but that might more challenging would be my thinking.

This is Libby. But if you are going in percentages of a neighborhood, of let's say 100 people, are you saying then that you are not allowed to have, of 100 people and only 4 people in the group home, and you are going to talk percentages, you still got to talk percentages. That means you could have two group homes with 100 people and only eight are disabled. And I don't know where it says we are limited--
It does not.
In any of the regulations.

And this is Libby. So if there is a Delaware law out there, and I don't know about all this stuff, that says only X number of people in a group home, and only 1 per development, and only 20% are whatever population, we need to know that, because it's not in any of these

documents. It's not in the federal documents, and it's not in the Delaware documents. I read through them all.

This is Terry. Let me clear that in talking with our court monitor, he said that the 2 and 20 rule, which applies to persons with serious and persistent mental illness does not apply to persons with intellectual disabilities in group homes.

What is the 2 and 20 rule?

That was part of the court mandate from DOJ for serious, persistently mental ill.

Settlement of psychiatric homes.

So we don't have to worry about the 2 and 20 rules. That is unique and limited to that population.

This is Melinda. One of the things, though, when we do go out looking for homes, they do tell us a saturation. If we can have apartments in certain complexes, they do tell us that, where did that come from?

This is Fran. That's the aftermath of the Olmstead Farm. And the court monitor, Bob Bernstein is speaking to the DOJ issue with mental health. I don't know if Delaware or DBS wanted the same kind of scrutiny, if that would apply.

Actually Jane might be somebody to have more information about that because she worked real court issue in Maine, so—

Again, this is Terry. I've talked about Bernstein. I've been present where he said, this is does not apply to the I-D-D service system in Delaware.
What this is saying--
If there was another court settlement, yes, but currently, no.

This is Kyle. It may not, but tends to look at how are we moving, where are we going to go, and if they made a determination about one population, what is going to happen in the future. I think you need to, even though it might not be specific right now, about how you need to do business, I think it shows and indication of how and what is going to be expected in the future on how to do business.

This is Gary. I have to say that the best way to look at this CMS rule is, what is best for the individual. A lot of them live in the setting they want to live. Out of homestead is the idea that folks should be able to live where they want to live, in a setting that is appropriate for them in the community. I am starting to hear more about the group aspect, that they are going to be located on grounds of institutions and such like that. That seems to be getting away from the idea of homestead. And getting away from what I think CMS is talking about.

The state behind, they were the person with variable specific needs, and that is what it is all about, as best as they can, and not too much of this people making decisions for them. That is the new approach. We are getting behind people with disabilities and assisting them or allowing them to determine where they want to be.

Kimberly.
This is Kimberly. What isn't the availability of housing in Delaware, so are we, is the policy in Delaware that you can't have two homes on the same street. It's very hard to find housing in Delaware.

Is that a policy?

I'm asking. Is it, what is the limit, is it 3 houses, 4 houses, what are we saying, to where it's not fully community integrated, there are so many of them in the same neighborhood, factoring that Delaware is a small state and finding these residences, apartments is rather difficult. I don't know if there is any rule from the division or whatnot on how they're going to proceed with balancing integration and choice and availability. I hope that makes sense.

It makes, this is Lisa Elias. That makes a lot of sense to me, because you were talking about North Dakota, and I believe one of their backups, their reasoning was where their real estate, a very sparse population, this is our situation, our immediate need for our state, and Delaware could do the same. From its side.

This is Terry, and I guess I want to suggest that we probably need to get back to the task at hand, but I guess the last comment that I would make, and I am not saying others can't comment, but, one of the realities, I know from having been a residential provider for many decades, is anyone that needs 24-hour services is going to need at least one person present for 24 hours, and often times that one person can serve 2, 3, 4, or 5 people. So in terms of economy of scale, let's use, I know some people don't like hearing this, but if we get to the point where we impose some sort of restrictive 2 and 20 rule, it may be progressive, I think what we have created is a system where fewer people are going to be served with the same amount of money because that is the only way they can be served. In the case of those persons who needs 24 hour services. If you are looking at people who need drop in supports, you've got a different situation. But I think if we're just serving fewer people to reach some ideal that is not practical from the perspective of the needs of all the people, I think we've gone the wrong direction, so.

This is Lisa. She's the timekeeper. (laughter)

This is Kyle. It think it's going to be up to CMS to determine that. We are going to do the best we can to try to put together a document self assessment. It goes back to what Shore said about, if you want to get Medicaid dollars, is this plan going to work for Medicaid to say okay, you are good to go.

This is Terry.

Hold on. Micki.

My name is Micki, and I think that CMS has specifically, that these will be consumer driven person centers. So if it's a consumer and they choose to live with others, who are we to say, the 2 and whatever rule is, well, you can't. If a consumer is driving it and it's a person centered choice, that is the most appropriate for each person.

This is Terry. Jane also mentioned several times at the joint finance committee in her opening remarks that the DDDS system, where currently it's I think 4 persons or maybe a few with 5 still, they are in the process of being downsized, that that is more progressive than probably 95% of the states out there, so I don't think we have to worry about falling behind the time.

Okay, this is Libby. We're out of time for South Dakota but we haven't really gotten past page 2. We are supposed to go through Tennessee next. Can I recommend that we just continue with South Dakota?

Yes. (laughter)

So let's move on to page 3.

This is Bill. The group homes. We have been trying to get members out of the group homes for Delaware people first.

Why?

To get them to come to Delaware people's choice. If 4 people are living in a home, 3 say they want to go and 1 say they don't, they don't go, and I think that is unfair for those 3 that want to go. They should be able to go, and not one person. But it's the caretaker has to take all 4. We've been trying to get group homes to join people first for years.

Is that true in all group homes?

All group homes.

No, it's not. And I've run group homes for many years.

Yes it is, because they are not joining the group homes. We know, I have many people in my homes—
Who are allowed to stay home alone. They can stay home alone while everybody else left. It is not true for all homes.

Perhaps the assessments rule will expose the individuals with the group homes that are doing it right and those that are not.

Good point.

It is an issue in some places.

Yeah.

Okay, 7. Individuals receive services in a different area of the setting separate from individuals not receiving Medicaid HCBS. That's pretty heavy.

Are you segregating people within the setting?

I am going to keep going unless somebody speaks up. 8, Does the setting isolate individuals from the broader community. I think that is very big.

This is one. This is Tim. When I looked at this again, I think of my son. Writing in his ELP, this is Doug. So I think providers can easily deal with this question, frankly, by referring it to the ELP or the Therap, as was suggested earlier. I don't know if you want to keep it in, but I think it's an easy question to answer.

Okay. Well, we're not saying in or out, we're just reviewing at this point, commenting. Anything else on 8? 9, does the setting restrict visitors?

This is Tim. That number 9 directly relates to the questions we saw in the tool instrument, and I think we already discussed it.

Does the setting restrict visiting hours specific by hours of the day, to specific hours of the day. Physical accessibility. Barriers that individuals are not able to open, move around, without staff assistance. Are there obstructions that limit individual's mobility. I think those are kind of more direct. Plants accessible to individuals. We are skipping through these pretty quickly, is everybody okay with these.

We're not voting anyway, it's more of a general comment period.

Yeah, but if there was an issue, I'd like to, if there's an issue with one of these questions, I'd like to see where the issues are. (beeping, like a foghorn) Is furniture placed to allow individuals to use furniture independently. Residence been modified to meet the needs of all individuals. Does the setting have stairs or steps. Ramps, elevators. Do individuals control his or her personal resources. Are individuals allowed to decorate. Do individuals and resident settings have lease agreement. Here we go, lease agreements.

This is Kyle. Just have a question on personal resources. What is the definition of that, is

that a common term that is used, I think you were mentioning--
Funds for sure.

I figured that would be part of it. Does it go beyond funds?

Personal possessions, yeah.

So funds and personal possessions?

For example, stereo. Is a person allowed to play stereo as loud as they want, 24 hours a day. This is Tim. Doesn't this question deal with the fact that some providers are there for all the transactions. And the banks know that as well. And we are in charge of their money and PSR's in case they are not in process, and they also sign--
The providers are not rep payees.

But the state are the rep payees for the residents.
Right.

So, this is Tim again. If we were answering that question from a provider--
I don't control their, I mean they—

Well, they do in the fact that they are there.

Yeah and they have access to spend—

So I think we're okay on this.

Their money is safeguarded.

So this is Terry. My understanding, for example, in CQL the person does not have their own mo in their possession, you have to explain why. That would be the expectation I would interpret this to expect. And you should be able to do that.

This is Gary. Is that something that depends on who has guardianship, I mean –

No. That's systemwide, isn't it, Fran? I mean all agencies are responsible for the managing the funds of the individual.

To whatever extent they can't for themselves.

And there are several laws that kind of limit – this to me speaks more to something like it – and this is a silly example, we get into it all the time. I decided that I want to have pizza and beer for dinner and bring it home. Can I share it with everybody in the house, or is that considered me using my money to pay for somebody else's dinner. I mean, that's silly, but

that comes up a lot. When you are looking at funds. Somebody paid for dinner that night. It depends on the individual.

And what Fran was saying, sometimes they feel that if one person has money and nobody else in the house does, so they buy the pizza. It's looked at as they are using their money to feed the entire house, which is a no no. So, just like people say I'm going to take you out to lunch, we are not allowed to have the residents take us out to lunch. It's part of the policy on financial expectation.

Okay. Number 4. People who are not participants or staff live in the setting. Is the setting identifiable as specifically for individuals who are elderly, disabled? Is that the one with the sign in the front? It does have signs in the front. Are there areas in a setting that are restricted to individuals that have not gone through due process? I have no idea what that means.

Can you explain that, group process?

I do have a question. As far as, it says, we, lobby, it says check in there, we don't, we have sign in books that the state it makes us set up when people come in the house. I mean I don't think people should that's really necessary have to sign in, but that's a state thing. This is Fran. I think that more is a question about, do you have to check-in in the lobby and have somebody come get you.

This is Terry. I think from a CQL perspective, it was, does the person have the right to go into the office area, to go into the kitchen, to go into the basement, and so on and so forth, and believe it or not, there are fire marshal laws that in some cases, if you don't have a 2nd knee rest from the basement, they can't go down there, so it typically became a team decision where you documented why a person couldn't have access to specific portions of the home, if that was the case.

This is Kyle. I think if you use any kind of form of this question, it needs to be rewarded. I just took out the words, due process. I think of the old type of –
Do individuals choose when, what, and where to eat. I think we talked about that.
Boy.

That's going to be an interesting one. Are requests for supports and services accommodated? Again, it would be good to define what services and supports, goes back to the other question. Is information about how to file a complaint grievance posted in obvious location? Understandable format.
Yes.
Can individuals make anonymous complaints.
Yes.
Can individuals lock their bedroom doors when they choose. Do individuals have privacy to perform personal hygiene. And the personal plans would come in here.

I'm sorry, Libby. This is Kyle. Going back to 10, can you explain how in a small environment you can make an anonymous complaint?

To whom? Like, is it to –

I said whom, so – it's just something to think about. You can say yes, but it's pretty hard to answer yes, but you guys can help explain that.

It's Melinda. We do. We have the complaint process. When people come in, we explain it. We leave it well posted in the house, and there's a number that they can call. So provided they are able to access the phone, use a phone to call. Their case managers also see them about monthly, and you know that is somebody from the outside they could make a complaint to if they felt –

It's required that we have the complaints policy, I mean the forms posted in a manila envelope if they ever want to, I mean they could do it or they could ask a staff person if they're not capable of doing it themselves if they feel like one of their rights are being restricted or something.

Yeah, this is Fran. It's not uncommon either for somebody to make it a day program and talk about something that's bothering them and the day program staff may say, why don't we give some privacy here. Here's the phone number. And then they don't necessarily have to give their own name.

And the other thing we do monthly, consumer meetings, we review their rights, like every month will review one or 2 of their rights, so we're always reviewing those things, reminding them that they have these rights.

And I understand and they might know their rights and you have to be wondering, how is it done anonymously. It's that word, anonymous. Is what I'm talking about.

So this is Fran. I'll just give you an example. I got a phone call several months ago from an individual who didn't want to be identified, but said that the group home they were living in didn't have food after a snowstorm. They didn't want to give their name, but we went out and investigated. It was anonymous complaint, and they were right. There was no food.
This is Gary. Was that a portable policy that was written or did that just kind of happen the way it happened?

There are phone numbers they can call, but this particular person I happened to have just met not too long before and kind of explained what my job was, and so they called.
But they told somebody to call me, I don't know if it was that exact person who called me.
Okay. So we're kind of out of time. We are at the wrap up point. We didn't make it through everything, but. So for our next meeting, what do people recommend for the agenda, I mean, how are we going to proceed? And if there are additional assessments that we could

take a look at before the meeting—

This is Tim. Fran, could you ask Jane or other folks here if there are any other state assessments that we ought to be looking at? If we have one or 2 more, I think that would be helpful.

Did you get receipt of the Pennsylvania plan?
No.

It was in the other work group, and so we did look at that this morning. So I can send it to you.

I think I might have it.
Okay.

But the other thing is on one of those websites it has, Lisa and Barb?
I'm sorry.

On one of the websites has, it includes this CMS approved plans, I don't know if any of these assessments are on that list or if we can, I don't know, but it would be nice to see if there was one that was proved. Maybe, Fran, if you could take a look at that.

This is Kyle. (inaudible) if there are plans out there, approved plans out there, that would be –

Is it enough to approve the transition plan? Did they approve the assessment tool?

The Medicaid office had to approve the assessment.

This is Fran. Ultimately we have to develop the assessment and approve it. It is the data that CMS wants but, I think one of the things that was interesting about South Dakota is that they had started that assessment before they send in the transition plan and they sent this in as part of the transition plan. Not every state has done that.

So on that website, whichever one it is, I don't know, has approved transition plans, so if we look at those that included the assessments in their transition plan, would you say those were approved assessments?

I wouldn't feel comfortable saying approved or not approved because again CMS hasn't made it a requirement that they have to approve the assessment.

Okay. So friend you'll be able to see if there are any other plans that we can take a look at?

So Pennsylvania's?

Pennsylvania is out there.

Is one that you'd like to see?

And then for our next meeting if we have maybe 2 or 3 addi assessments that we could approve or take a look at before the meeting , what do you recommend for the meeting? Do we just review those and talk about again what we like and don't like?

Finish going through this one and –

Finish up on the agenda items, this is Gary, that we didn't finish today.

Okay. And again if you have any other agenda items, let me know by Monday. Our meetings are scheduled for weekly on Thursdays, 130 to 330 in this location through Thursday, June 11. Every Thursday until, unless we decide that we don't need to meet. So I recommend for next week we go through a couple more assessments, just discussing them and then maybe after next week's meeting we started talking about what are we going to include in our plan.

Sounds good.

Anybody have anything else?

This is Micki. Maybe highlight the ones, if we go through, each person highlight and see which ones you'd like.

So 130 next week?

130 next week.

Thank you.

Anybody have anything else?

Finished early. All right.

Thank you.